

FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

Chronic illness

Ten to twenty percent of children have a chronic illness, such as asthma, diabetes, cystic fibrosis, eczema or arthritis.

Like all other children they need to be part of:

- family life (play, chores and daily activities),
- social life and relationships with family members, peers and others,
- educational activities,
- leisure activities.

Like all other children, their growth and development into happy, well-functioning adults is supported by many factors. These include:

- personal qualities (optimism, coping skills and confidence),
- family supports,
- community supports (friends, peers, schools and social networks),
- health and medical supports (medical advice and management, medications, physical, psychological, occupational and other therapies),
- societal supports (financial benefits and government policies).

For all families, life can become harder when experiencing:

- uncertainty (not knowing what to expect with illnesses),
- changed circumstances (such as moving house),
- money problems,
- child abuse,

- marital conflict and separation, or adverse life events and losses (including the death of a family member),
- life-threatening experiences.

In families where a child is affected by chronic illness, there can be additional challenges for the child, the siblings and the parents. While some are general effects of chronic illness, others are due to the specific condition.

- Developing self-esteem and a healthy body image.
- Entering new phases of life (puberty) going into high school.
- Feeling different, looking different (visible versus invisible condition), depression.
- Longer dependence on parental support.
- Limitations caused by the illness due to fatigue or pain.
- Challenges on everyday activities.
- Restrictions on peer relationships (physical limits on involvement; not being understood by friends or peers).
- Difficulties in peer relationships due to changes in the patient's thinking or emotions.
- Loss of control over life.
- Restrictions on holiday or recreational activities.
- Restrictions on parental employment, promotions or recreation (no "time out").

Children can react in different ways to stressful experiences. Their reaction will be different depending on their developmental stage. Some show little effect, others may have several of the following.

- Behavioural problems (angry, aggressive, withdrawn or risk taking behaviour, poor sleeping or eating pattern).
- Illness and treatment related problems (denial of illness, refusal of medication, changed attitude to illness during adolescence, illness can become the focus of struggle between the young person and the parents).
- Psychological problems (sadness, fear of separation, excessive worries about health, feeling hopeless and powerless, giving up, irrational guilt for causing illness or burden to family).
- Relationship problems (peer problems such as with joining in or being teased, being treated differently and not feeling like one of the crowd, missing school and excursions; conflict with parents because of high dependency, high levels of concern by parents, and lack of understanding about why limits are necessary; conflict with brothers and sisters because of rivalry for parental attention).
- School and educational difficulties (concentration and learning problems, difficulty keeping up, multiple absences).

Most families manage well, using a range of coping strategies and benefiting from the support of their family, friends and care providers. Good communication between care providers and families is important. Keeping care providers up to date about changes in needs or need for help is really important. Help is available from general practitioners, social workers, community workers, paediatricians, mental health counselors, CNC's or psychologists.

Young people should be encouraged to become involved in making decisions about their care and in choosing who they will talk to about psychological issues. It is important to remember that a young person will outgrow their child health service and will need to transition to adult services. This will be discussed with all young people with a chronic illness.

Help and support is available depending on which chronic illness your child has. You may be able to access the following:

- Home help, home modifications.
- Transport support and assistance with parking permit.
- Educational and schooling support.
- Psychological counselling (individual, marital, family counselling).
- Medical advice and management, pain management.
- Financial assistance.
- Carer's support, employment support
- Respite care.

Depending on your child's condition and ongoing support needs, they may be eligible to receive supports under the National Disability Insurance Scheme (NDIS). The NDIS supports children with a permanent and significant disability as well as providing early intervention to reduce the impact of disability in the future. It provides you with more choice and control over how your child is supported to participate in the community and achieve their goals. In order to check your child's eligibility, please visit www.ndis.gov.au or make contact NDIS on 1800 800 110.

For further information or for referral to support agencies call the Association for the Welfare of Child Health (AWCH) on 1800 244 396 or visit www.awch.org.au